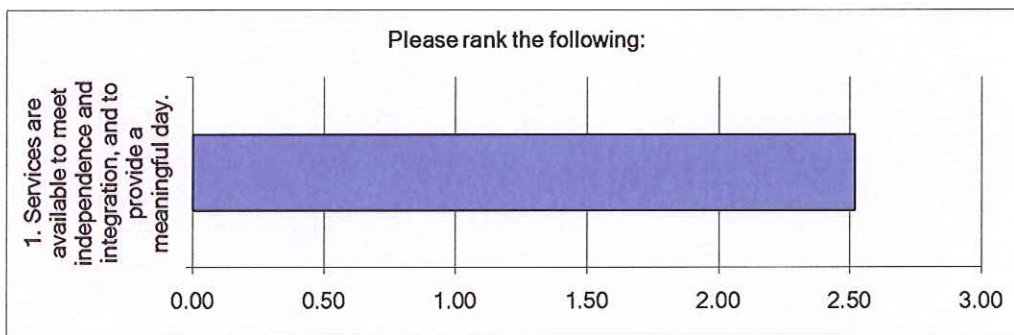


Advocate Survey Responses State Plan and Waiver Amendment March 2010

Please rank the following:

Answer Options	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
1. Services are available to meet independence and integration, and to provide a meaningful day.	7	14	19	6	2.52	46
If not, what services should be developed?						29
<i>answered question</i>						46
<i>skipped question</i>						4



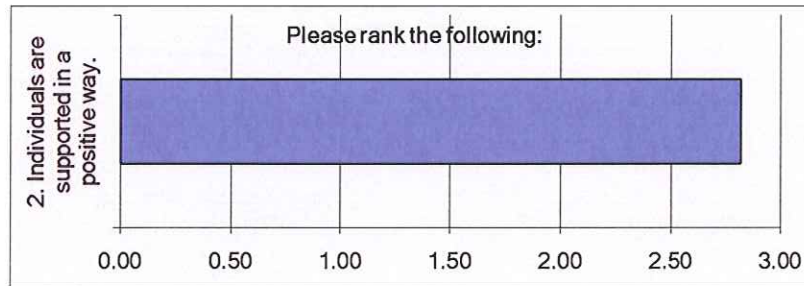
Responses:

1. There was a movie a long time ago. The title was I know what you did. We, as the people of Nebraska, now know how you are cheating to steal hours of service from our people who need help instead of something else.
2. The tests that get how many hours a person gets are illegal. The state has gotten by with that for a long time. Now people know about it and are going to demand to see what is used and want to get answers more than "We use other things as well" and when we ask what other things, we just get "Other things".
3. Use legal assessments instead of the ICAP which is NOT to be used to determine hours (Manual p. 38).
4. The state needs to be sure that our aging DD population is being funded to meet their increased level of need. An IER was completed and she did receive an increase in funding, but there are so many other individuals who are being funded at the level they need to meet their increasing needs as they have aged. The state needs to be sure they are evaluating the appropriateness of the funding being provided and increase/decrease as needs change. My primary concern is for folks who are aging in the DD system and have never had any adjustments made to their funding since their funding was originally determined almost 20 years ago!
5. A program of job training for ALL abilities. An educational program for employers in community so they make a commitment to people with disabilities.
6. Supportive services.
7. We need more providers in the Central and Western Service areas as well as money to pay for mor qualified staff.
8. More flexibility in staffing.
9. What has been proposed is fabulous!
10. Disagree/Agree: Not always, your trying, thanks. Picking up a drive through burger is not an outing in the community example.
11. Agree, if you know to ask.
12. Unknown
13. Advocacy Services
14. More meaningful jobs in the workshops.
15. Yes, but we need more choices.

16. Having someone from the state to assist with IEP's would be great.
17. There needs to be services that provide a variety of activities for consumers, such as daily living skills, community activities, as well as work skills.
18. A bus that travels all through Omaha meaning to Village Pointe and Elkhorn.
19. 1. Not enough services to meet demand.
2. We had an individual with Prader Willie Syndrome and the staff were not educated as to how to keep him safe. There are no PWS specific services in NE; however, some education could be provided when needed.3. We have had individuals who have a mental illness along with DD and have not been allowed services or discharged services with a good plan.
20. If a person is on the waiting list and funding becomes available there should be staff available with the various agencies to meet those needs.
21. In Lincoln, there are a variety of services available, probably because there are more persons needing services and more providers to provide some competition of services and quality. In rural areas, the choices are fewer and the travel time has to be figured into what is available and appropriate.
22. It is hard to find jobs where physical labor isn't involved.
23. Services for 18-21 are severely lacking.
24. Too many people who receive employment services spend days doing nothing.
25. Staff training/education is lacking in regards to teaching adults and working with behavioral concerns. Many services are not geared towards meeting those needs of those with severe disabilities and result in being adult baby-sitting services instead.
26. Services remain in many locations segregated do not foster independent skills while day activities are "buy work" oriented in nature - they are meaningless. New models must be trialed and incentivized, for example increased in-home services and competitive employment supports. The service system lacks true individual and family centeredness.
27. More supports for dually diagnosed (mental illness and intellectual disability) individuals should be provided.
28. Integration and meaningful day is not met at all. Independence for some but not the majority.
29. But it depends on the provider. People need real jobs, more options in services, and a greater ability to direct their own services.

Please rank the following:

Answer Options	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
2. Individuals are supported in a positive way.	5	5	33	6	2.82	49
Comments						20
<i>answered question</i>						49
<i>skipped question</i>						1

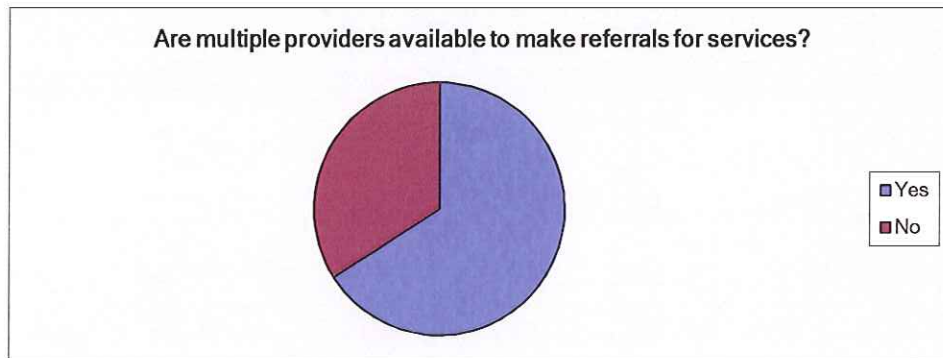


Responses:

1. If the people are able to take care of themselves, Nebraska is fine, but for people who really need more hours, Nebraska is heartless and wants to put people where they do not fit and have them away from their jail cells for 15 minutes a day and that is called Community Vocational Development. I would be ashamed if I were you. The people know.
2. The state system serves what it wants, not what people need.
3. People who are not severe profound or mild are not considered as individuals and their needs are not met.
4. Depending on staff assignments.
5. Region V-LEAP and ILC have done a great job to help support my sister. She had developed medical issues during her aging process and they have worked very hard to help meet her expanding needs.
6. Checked both Disagree and Agree in this section. Then stated the following: somewhat not for supported employment.
7. If you have a good Service Coordinator like we do then then answer is yes. If you have an unsympathetic SC, then no.
8. Our folks are good at staying positive.
9. This is what I understand.
10. Changed "individuals" to "people".
11. Okay now. In the past I have had education concerns.
12. Some staff are positive. Some staff do not promote independence that some consumers have the ability for. Some staff are negative and impatient with consumers.
13. We have been fortunate in having direct care staff that have been very supportive.
14. Staff can be an issue.
15. Same
16. Not if they are not supported by staff in their homes, they have to do what staff wants.
17. While many staff try to support individuals they work with, many providers fail to provide their staff the education/understanding in treating adults as adults and not children. Lack of education/knowledge of setting up support structures for individuals to make them successful.
18. Too many examples of the converse having occurred, especially in congregate care settings like BSDC. This won't change until we build a trained, supported, and reasonably compensated workforce in DD services and move services entirely into the community (and not just 8-plexes or apartment complexes- real homes!)
19. The care staff schedule is met first and foremost. If they feel positive then maybe the DD person might feel more positive.
20. Again, it depends a great deal on the provider. I think most providers are trying within the current array of services.

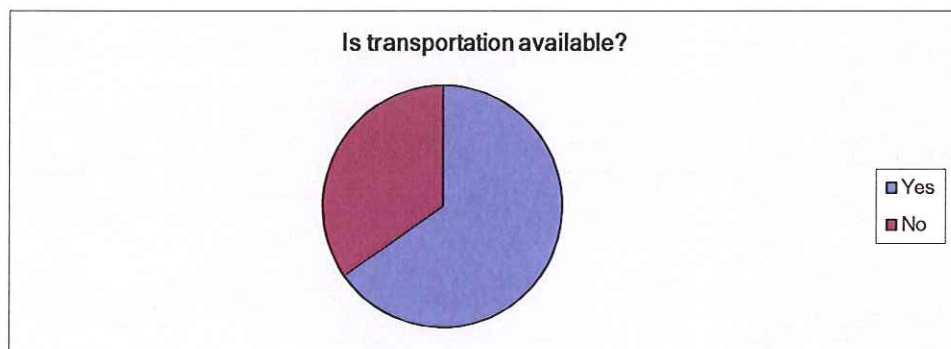
3. Are multiple providers available to make referrals for services?

Answer Options	Response Percent	Response Count
Yes	65.9%	29
No	34.1%	15
<i>answered question</i>		44
<i>skipped question</i>		6



Responses: NONE

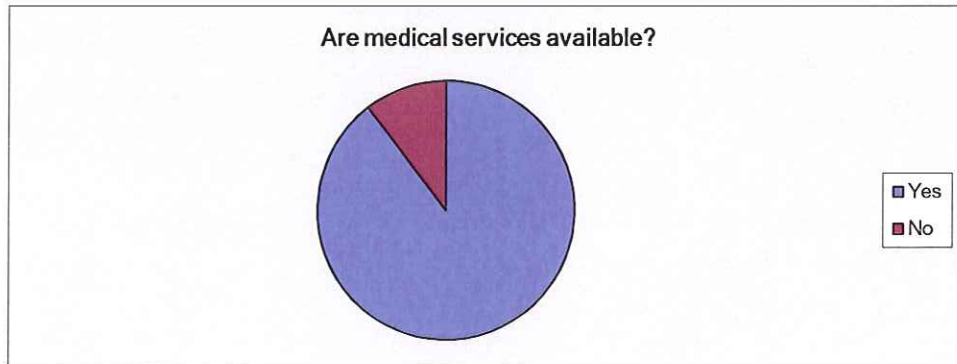
4. Is transportation available?		
Answer Options	Response Percent	Response Count
Yes	65.3%	32
No	34.7%	17
<i>answered question</i>		49
<i>skipped question</i>		1



Responses: NONE

5. Are medical services available?

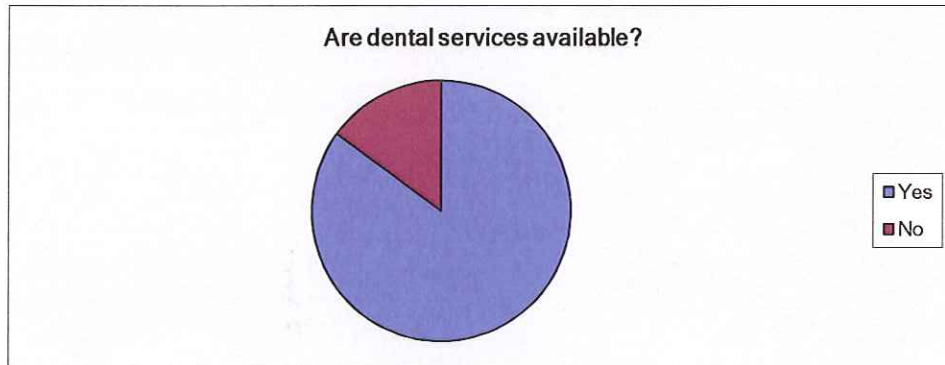
Answer Options	Response Percent	Response Count
Yes	89.6%	43
No	10.4%	5
<i>answered question</i>		48
<i>skipped question</i>		2



Responses: NONE

6. Are dental services available?

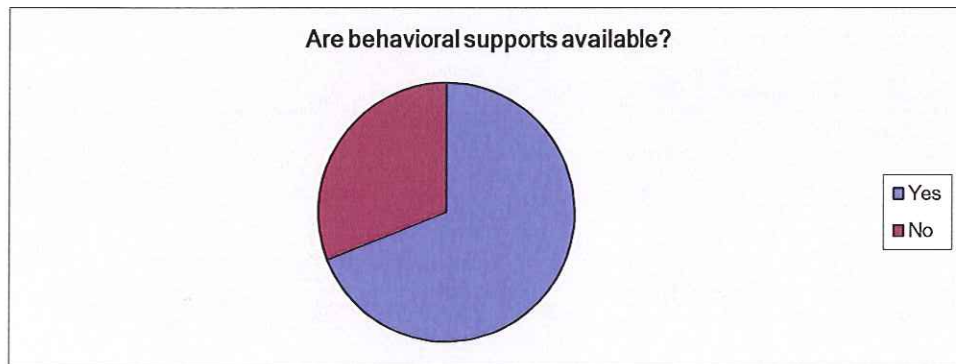
Answer Options	Response Percent	Response Count
Yes	85.1%	40
No	14.9%	7
<i>answered question</i>		47
<i>skipped question</i>		3



Responses: NONE

7. Are behavioral supports available?

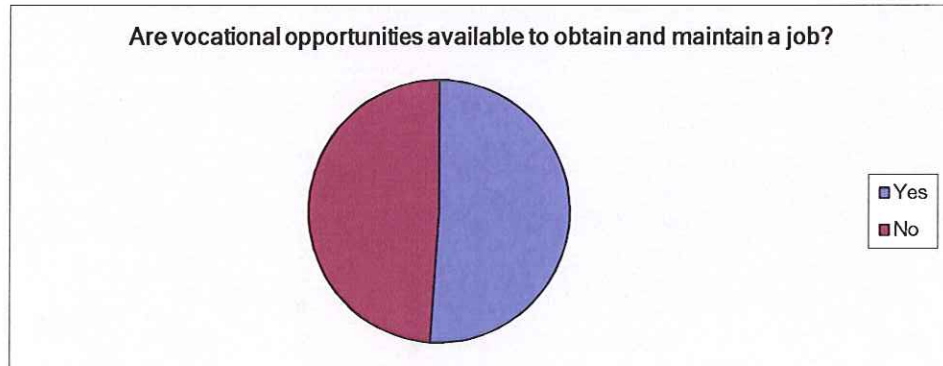
Answer Options	Response Percent	Response Count
Yes	69.0%	29
No	31.0%	13
<i>answered question</i>		42
<i>skipped question</i>		8



Responses: NONE

8. Are vocational opportunities available to obtain and maintain a job?

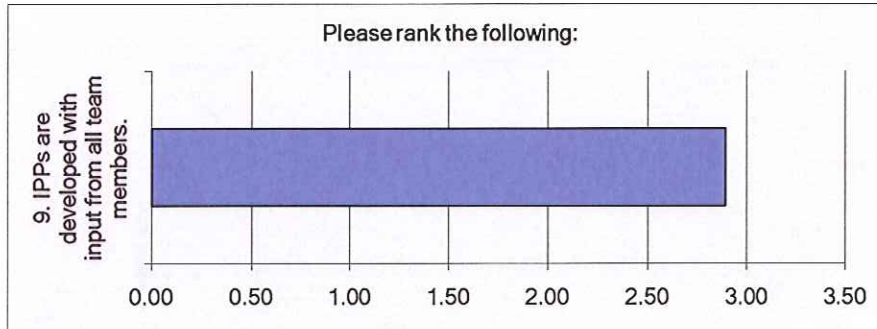
Answer Options	Response Percent	Response Count
Yes	51.1%	23
No	48.9%	22
<i>answered question</i>		45
<i>skipped question</i>		5



Responses: NONE

Please rank the following:

Answer Options	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
9. IPPs are developed with input from all team members.	5	6	24	11	2.89	46
Comments						19
<i>answered question</i>						46
<i>skipped question</i>						4

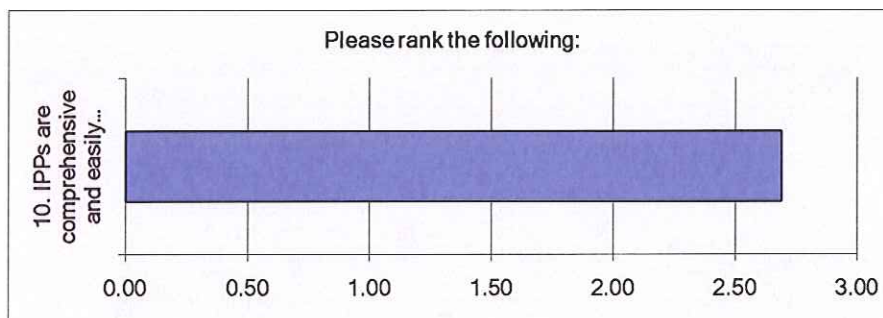


Responses:

1. Plans cannot be made when people don't know what somebody needs.
2. A plan cannot be made because the time is not true to what a person needs.
3. People who are functioning above severe/profound are not offered enough hours to develop a proper IPP.
4. Only if they are completed correctly.
5. Depends on Service Coordination.
7. Not always carried out.
8. I have a large team we all have input.
9. It is always the same and never really is meaningful.
10. N/A
11. Some guardians and provider staff have stated that the new IPP format does not give opportunities for input from the family/person served.
12. Yes, but frequently there are no checks on follow through.
13. All team members are given an opportunity to add to the IPP, but some do not choose to do so. The company that provides OT and PT for my daughter does not allow for the therapists to attend IPP meetings. The only way we had the OT attend was to give up the therapy time for the week and plan the IPP for the normal therapy time.
14. DD people don't show up for transition IEP meetings till the very last couple of years, yet parents and the school have to begin planning at 16.
15. The only want input from those that agree with them.
16. The more severe the individual's disability, the less likely an attempt is made to involve that person.
17. IPPs are often developed before the meeting starts, and the team just goes through the motions. Individual preferences are honored only if convenient for the provider.
18. Most DD persons go along with providers.
19. But staffing plays a bigger issue than it probably should in what is actually offered.

Please rank the following:

Answer Options	Strongly Disagree	Disagree	Agree	Strongly Agree	Rating Average	Response Count
10. IPPs are comprehensive and easily understood by all team members.	6	9	23	7	2.69	45
Comments						16
<i>answered question</i>						45
<i>skipped question</i>						5

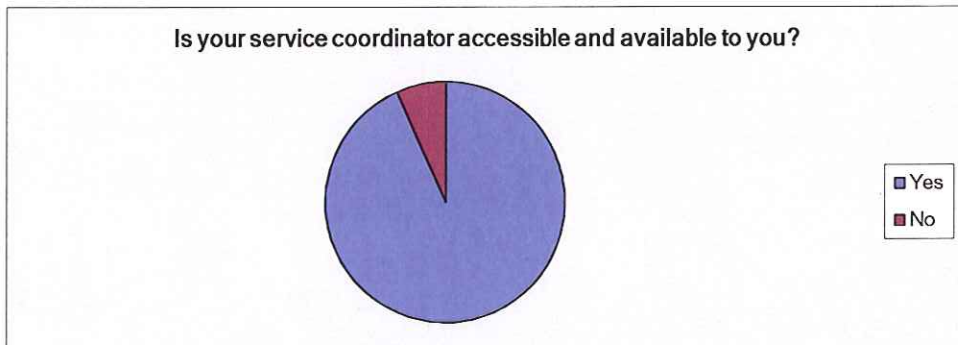


Responses:

1. Info is based on lies.
2. The things are made for people who can read and write, not for the people they are supposed to be for.
3. They are based on State Needs and not the individual's needs.
4. The new changes that have been implemented appear to be more focused on appropriate/acceptable wording vs what the team wants to convey as important for the person. Donna Ray has done a wonderful job to work through the changes in the most positive way possible. However, being a member of other teams, the changes have been more challenging to work through.
5. My brother would not understand it. I also found it to not be user friendly or easy to read.
6. We work very hard to get everyone on one page.
7. As guardian I don't always understand the "lingo" and how programs are run/evaluated.
8. N/A
9. I think many parents are confused by all of the forms and acronyms used. I feel it is WRONG to have the IPP in the "I" form. How do we know, for those consumers who are nonverbal, what they want? We are putting words in their mouths when the forms are phrased with "I want...". There is working that can be used that would be more accurate so that we are speaking for the consumer. Only he/she KNOWS what they want?
10. Sometimes guardians/family have expressed that the new IPP format is difficult to understand and navigate through at IPP meetings.
11. I have found the IPPS are often idealistic. Many items on the IPP do not happen.
12. I understand most of the "rules" about what goes on the IPP - that goals have to be measurable and be working toward growth. However, the IPP does not reflect those goals that are not measurable, such as to enjoy activities with other persons or to have opportunities to interact with persons outside of the family.
13. Parents of 18-21 year olds don't even know what a IPP is because the DD people aren't at the IEP meetings.
14. Written for state compliance, not for advancement of individuals.
15. IPPs are not adequately comprehensive when it comes to planning implementation and monitoring.
16. Not all DD persons.

11. Is your service coordinator accessible and available to you?

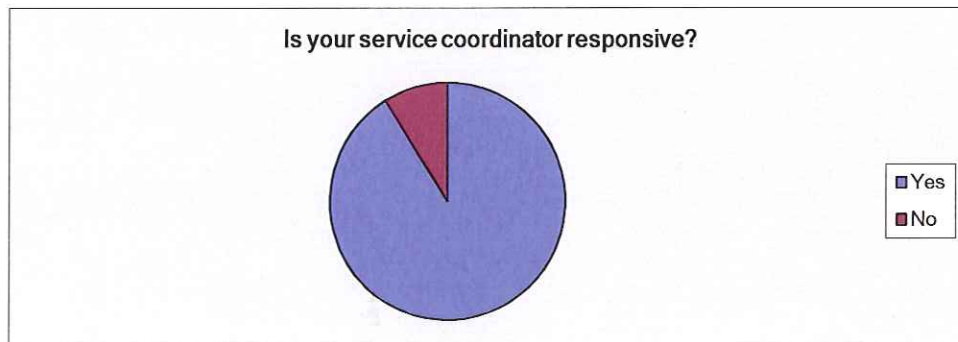
Answer Options	Response Percent	Response Count
Yes	93.3%	42
No	6.7%	3
<i>answered question</i>		45
<i>skipped question</i>		5



Responses: NONE

12. Is your service coordinator responsive?

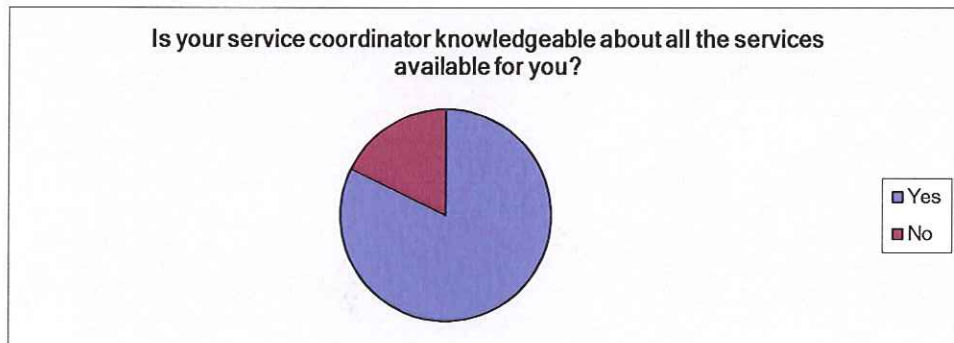
Answer Options	Response Percent	Response Count
Yes	91.1%	41
No	8.9%	4
<i>answered question</i>		45
<i>skipped question</i>		5



Responses: NONE

13. Is your service coordinator knowledgeable about all the services available for you?

Answer Options	Response Percent	Response Count
Yes	82.2%	37
No	17.8%	8
<i>answered question</i>		45
<i>skipped question</i>		5



Responses: NONE

14. Is your service coordinator respectful and supportive?

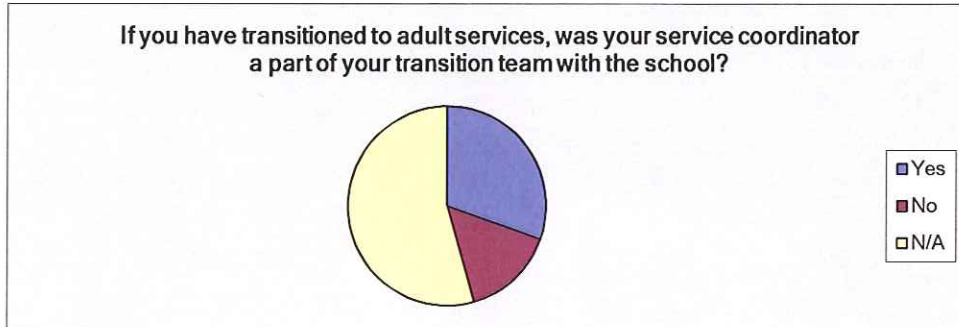
Answer Options	Response Percent	Response Count
Yes	90.9%	40
No	9.1%	4
<i>answered question</i>		44
<i>skipped question</i>		6



Responses: NONE

15. If you have transitioned to adult services, was your service coordinator a part of your transition team with the school?

Answer Options	Response Percent	Response Count
Yes	30.4%	14
No	15.2%	7
N/A	54.3%	25
<i>answered question</i>		46
<i>skipped question</i>		4



Responses: NONE

16. Any additional comments:

Answer Options	Response Count
	33
<i>answered question</i>	33
<i>skipped question</i>	17

Responses:

1. My Service Coordinatore is good. The rules are terrible because they are for the state, not for the people.
2. It is sad that the State of Nebraska resorts to illegal testing instead of using appropriate instruments.
3. #5 - Arranged by family. #6- Arranged privately by family. #7 - N/A
4. Donna Ray has been absolutely fabulous. She is an extraordinary person who truly seems to care about my sister and what is in her best interest. She provides information in a factual manner and does what she can to support what *(name removed)* team believes to be in her best interest. She reviews prior IPPs to ensure previous agreements have been followed through by team members and works with the team in a respectful, positive way to ensure any loose ends are completed. She is very organized, knowlegable, caring, responsive, reliable, plus a whole lot more. She deserves an award and a raise! I am so thankful for everything she has done, I don't even know where to begin expressing how wonderful I think she is. I hope the State recognizes her efforts and is as thankful as I am to have her be on our team!
5. Had day services only. There is nothing to do in workshop for day services. We color pictures, work on puzzles, do arts and crafts, go swimming and bowling. We need a job training program for ALL abilities and employers who will step up and make a committment to people with disabilities.
6. If you have a good SC then things go well. If you have an SC that does not know what they are doing or is not caring then it is more difficult for families.
7. Could not answer all the questions because my son 13 just transitioning into adult services.
8. #4- But often an issue; who pays? When available? #7-OMNI has been occassionally helpful.
- #8- Some barriers here. #13-Many newbees don't seem to understand even the basics of the DD system. #15-Surprised in Omaha. OPS does not reach out to SC and parents don't know to ask for SC involvement. The was never a problem in NE.
9. The proposed changes are terrific. We all need to keep mvoing forward. #7-hard to find behavioral supports. #11-but we have had 2 changes that we were not notified.
10. #3, #4, #5, #6, #7 - don't know. #11-I know families wo can not get a Service Coordinator to call back, even after many voice messages. #13-Not all Service Coordinators know about options available or how to access services in the systems. #14-I will not respond to this question.
11. #3-Don't know what this means. #7-Don't know. #8-Good job-positive changes, thanks. Please refer to people with disabilities as people - NOT individuals or clients if we are really wanting folks in the community.

12. I am fortunate to have great services for my girls. I would like to see payment for a caregiver going on vacation with us. #1-IF you know to ask. #4-But not public. #11-I am very lucky. #13- But I asked for someone who knew at least as much as I do.
13. Thank you for the commitment to the individual.
14. It has been difficult to learn how services and units work, and what services are available, but after 7-1/2 years in "the system" it is starting to make more sense. Thank you for the changes you are working towards. #3-not totally somewhat. #7-Not totally. I needed to access personal contacts to assist. #8-somewhat. It is difficult to change the attitudes of employers in small communities to give individuals a chance. #13-for the most part we have experienced a few misunderstandings but overall she has been helpful. #14-at first we had some difficulties with miscommunication and me not fully understanding everything but things have improved. #15- there was only 6 months between school and adult services so there was not much time to get things in place.
15. Verbal communications -speech - more available. #3-define providers - are they Service Coordinators, etc.? #8-provider continues to seek opportunities.
16. Too many employees are not qualified. They are low income needing a job. Smoking, pregnant and not married. Not the best example for handicapped person.
17. Service Coordination is our guide, friends and lifesaver. Please pay her more money as she
18. There is not a lot of Dentists that take Medicaid no-where.
19. It would be nice to have an inservice on what a Service Coordinator should provide to families, and what services are available. As a therapist, I would like to know what services are available to my consumers and an explanation on waivers, forms, etc. would help me understand things better as well!
20. I did not answer the last 5 questions, because I am the Service Coordinator and did not feel I could answer these questions objectively.
21. Difficult to find services for autism spectrum disorders, more education is needed regarding mental health diagnosis/needs concurrent to DD diagnosis; a lot of times workers provide treatment for mental health symptoms as behavioral issues, which is not always the case. More integrated treatment is needed in this area.
22. I would strongly suggest doing the ICAP the year prior to the student transitioning since it would then allow time for preparation during the last year of that program to train the student in the job that they would be transitioning to. To have the hours designated two or three months prior to graduation is not enough time to figure out supports.
23. She was a part of the team for three or four years and was invaluable as we prepared for and made the transition.
24. I could not answer some of the questions, because despite my adult child having an IQ under 70 and having all the criteria (except mobility issues) to qualify for DD services, she is denied services. The system is inconsistent and subjective. Thank you for giving me the opportunity to express my anger.
25. The more people I talk to, Service Coordinators are not part of the high school teams. Something needs to be done about the lack of transportation in Nebraska. I live in Omaha.
26. DD services are limited to IQ. People with very low social skills should also be included.
27. Some Service Coordinators need to be more informed about services that they are at present.
28. We are fortunate to have a very good SC. We had to fight to keep her. Have seen too many examples where SCs did paper work (sometimes) in lieu of actually coordinating services.

29. Dona Deal in Omaha is my son's Service Coordinator and she is excellent. She is always available when I have concerns or questions.

30. I think Service Coordinators should be able to transport individuals in the vehicles provided to them by the State. The decision to eliminate this service was not client centered whatsoever and works to weaken the relationships that the Service Coordinators have with the individuals they serve. Evidently whoever made this policy is ignorant of the importance of personal relationships in providing excellent services to individuals and is also not client centered in their actions.

Thanks

31. Once in services the mentality is I have to do what they say, no matter what.

32. The changes to the Medicaid waivers sound like they will really help the system more toward giving people more meaningful lives.

33. *(Name removed)*, my son, is successful in maintaining his employment because Career Solutions, Inc. provides proactive, preventive (PRN), vocational interventions through an employment specialist to help *(name removed)* respond appropriately to stress, tension and emotional worry when changes occur at work. His preventive, sporadically needed and provided ("What to do when you don't know what to do" and other emotionally charged concerns) services are working and have been successful not only for him, but also for his employer. Please do not include in the rewrite of the Waiver Amendments changes that would limit this important vocational services to a length of time (12 months, 24 months, etc.), or reduce his access to this successful vocational support and put him at risk.